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ABSTRACT

Developed by an outreach project for handicapped children 0 to 5 years of age and their parents in rural Maine, these 18 bulletins address topics related to living with a handicapped child. Directed toward parents, the bulletins touch on the following topics: parents' feelings, handicapped children's needs to be treated as normally as possible, ways to build self esteem, approaches for fostering independence, effects on marriage, the single parent, siblings, changes in family life, coping, reactions of others, encounters with professionals, the parent-professional relationship, education, early intervention, use and misuse of labels, therapists' roles, mental health professionals, and advocacy. Bulletins are written by parents and professionals and include a list of recommended readings. (CL)

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A Handicapped Child in the Family

Readings for Parents

Washington County Children's Program Outreach Project
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A Handicapped Child in the Family

Readings for Parents

INTRODUCTION

This set of eighteen bulletins covers a variety of topics of value to those living and working with handicapped children - in particular their parents. We have attempted to go beyond the issues of general parenting to specifically address in simple, concise format some of the problems unique to families of children with disabilities.

These 1-2 page bulletins are designed to be easily reproduced. As a series or singly, they are appropriate for use by individual families, parents groups, and staff. Also, consider using the bulletins, or parts of them, as news articles, program newsletters, or in public service announcements.

We would like to acknowledge the "Family Living" series developed by the staffs of the ERIC Clearinghouse on Elementary and Early Childhood Education and the University of Illinois Cooperative Extension Service, which was the inspiration for our bulletins.

A Handicapped Child in the Family began as a joint project of the Washington County Children's Program Outreach Project and the Maine Early Intervention Consortium: the Infant Development Center, South Portland, Maine, the Hancock County Children's Center, Community Health and Counseling Services, Ellsworth, Maine, United Cerebral Palsy of Northeastern Maine, Bangor, Maine, the Washington County Children's Program and its Outreach project, in Machias, Maine. Over the year, it has become the dedicated and cooperative effort of many Maine professionals and parents who have willingly shared their feelings, expertise, and time.

Catherine Bell
Coordinator and Editor

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Readings for Parents

No. 1

YOUR FEELINGS AS PARENTS

Will our baby have red hair? Blond? Brown? Will she have brown eyes or blue? Will he look like me? All these questions are in the thoughts of parents expecting a child.

The birth of a baby is one of the most exciting events in life. You prepare for it in many ways. You expect to love and be loved and to share the joys of watching your baby grow. The idea of creating a new life through giving birth is awesome. You look forward with excitement to having a healthy, beautiful child.

When you learn that your newborn has a handicap, you experience disappointment, frustration, and sorrow over the loss of a "perfect" child. You may have feelings of denial, guilt, and anger. These responses can be called "chronic sorrow," an O.K. process to go through. You need information, guidance, and support from people who are sensitive and responsive to your needs.

Denial

Your first response may be disbelief of the diagnosis. You are stunned, and experiencing emotional numbness. At this time, you accept the diagnosis intellectually but not emotionally. You keep busy to resist the stress you are under.

Each parent deals with this crisis in his or her own way. One parent may assume the "strong role," while the other has difficulty accepting the situation. Later on, these roles may be reversed.

Guilt

Parents almost always wonder, "What did I do wrong? Why has this happened to my child?" It's O.K. to yell, scream, or cry. Ask questions about what happened. Information from doctors will help you. Talk about your guilt feelings - they need not prevent you from doing a fine job with your baby.

Anger

When doctors, nurses, friends and family members do not understand your feelings, it is normal to feel angry and lash out at them. Also, you want to find any clue as to the cause of your baby's problem and that is not always possible.

One mother reported, "I was angry and hated him (the baby) or hated myself. I was responsible."

In many cases, anger comes from fear as well as resentment. Parents are afraid for their babies' lives, despite strong reassurance.

Attachment

The bonding of parent and infant is called "attachment." For two people to become attached, there must be a give and take. Falling in love with

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a baby is like falling in love for the first time. Remember when you first smiled at someone special and the smile was returned. The response encouraged you, and over a period of time you found yourself becoming closer to that person. With no encouragement, you would have lost interest and a chance for attachment.

The same is true between infant and parent. Your baby's physical or mental handicap may be a barrier to forming an attachment. It may prevent natural, loving responses between you.

A baby born with a cleft palate has trouble sucking and may be difficult to feed. Due to hypersensitivity, a premature infant may respond to touch with screams. A parent may avoid giving eye contact to a baby who is physically unattractive. What are usually close, sharing times between parent and child become stressful. This is an obstacle to attachment.

Grieving

Falling in love with a baby takes time. For many, the process begins even before the birth. If your baby is born with a handicap, you may feel sorrow and confusion because this newborn is not the child of your hopes and dreams.

Parents must be allowed to express their grief and feel the sorrow of their loss. This is a natural healing process through which they are able to accept their newborn child. Too often parents have been taught to "keep a stiff upper lip," not to show grief outside the privacy of their homes. This can work against your acceptance of the reality of having a handicapped child.

Acceptance

All children have their ups and downs and give pleasure as well as pain to their parents. The process of acceptance can be learned and is ongoing. Strengths and weaknesses must be shared. When a mask is worn, when the family avoids reality, there is loss of connection and disjointedness.

For a family with a handicapped child, the denial, guilt, and anger may repeat themselves throughout life. As they work their way through these feelings, parents are able to "fall in love" and grow with their child.

Suggested Readings:

A Difference in the Family by Helen Featherstone, Penguin Books, 1980.

A Reader's Guide - For Parents of Children With Mental, Physical, or Emotional Disabilities, U.S. Department of Health, Education, and Welfare, 1979. (For sale by Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402, Stock No. 017-026-000-58-5.)

"Chronic Sorrow: Parents Response to the Birth of a Child with a Defect" by Ruth K. Young, The American Journal of Maternal Child Nursing, January/February, 1977.

"Help for Coping with the Unthinkable" by Rod Ballard, Developmental Medicine and Child Neurology, August, 1978.

Prepared by Melissa Harrison, Outreach Coordinator, and Anne Chaisson, Social Worker, South Portland, ME.

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Readings for Parents

No. 2

HANDICAPPED CHILDREN ARE "KIDS" TOO

Most of us have had a child tell us which toy he would like to play with or what she would like to do. What about those children who have difficulty communicating their wants and needs to us because of some type of handicap? Should we treat them differently because it is hard for them to communicate, or walk, or move about? Should we expect less of a child with a disability? Should we do everything we can to aid this child so he always has something to do and never becomes upset or frustrated?

We should treat a handicapped child just like any other. The fact that a person is handicapped does not mean that he or she has different emotional, physical, and social needs from other children. I have learned that kids with disabilities enjoy the same types of activities, toys, attention, and responsibilities as all children. They know what they like and don't like, what they want and need. They are the real teachers and we can learn much from them.

Each child, no matter how handicapped, finds his own way to communicate with others. We must listen and watch to pick up their sometimes subtle clues and respond to them.

Handicapped children are kids! There are certain things we need to remember as their teachers, parents, and friends.

1. Children with handicaps need to grow and develop to the maximum of their potential. We have to give them the chance, the time, and the means to learn to feed and dress themselves, to communicate, to develop academic skills, and to socialize. It's often easier and faster to do things for these children - even to think for them. Yet, if we take the time to teach them now, we save time later when they can help themselves. They will feel better about themselves, too.

2. They need to feel like a contributing part of a family or group. Give them some responsibilities. Have expectations for them, no matter how small they seem to you. Children need to develop a feeling of self-worth, but they can't if we don't give them the chance, or if we do things for them.

3. They need to feel that someone is "listening" to them, even if they can't express themselves verbally. Watch for sounds, body signs, and facial expressions, which are a part of total communication. Remember that children may understand perfectly well what is happening or being said around them. No matter how disabled, they are still aware of changes in attitudes, voices, and facial expressions.

4. They need to play, experiment, try and feel new things. Expose them to new experiences and people. Take the

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child who spends hours in a wheelchair and let him play on the grass, in the dirt or water - anywhere that is safe for him. Go to the grocery store, to the circus, or on a picnic. Don't overprotect them.

5. They need to experience sensations which are a natural part of development for most children. A child who cannot run may enjoy the sensation of being carried by someone who is running. What about spinning around to get dizzy? This sensation can be provided for a physically handicapped child by rolling, spinning in a swing or in our arms. Of course, caution must be taken if the child has a seizure disorder.

6. They need to be allowed to have and to express different emotions. Don't expect them always to be happy. We all have days when we're in a bad mood or could care less what is happening. Kids have a right to these days also, even if it isn't convenient for us.

7. Above all else, kids need to feel loved.

It is important for us to remember that all children have similar needs and rights, regardless of any handicapping conditions. The other day in the school cafeteria, a woman saw a severely handicapped child and said, "It's too bad that child has to come to school." I bit my tongue and replied, "She really enjoys coming to school and participating with the other children."

There are still many people not aware of handicapping conditions, nor of the needs of handicapped people. There was a time not long ago when I was totally unaware, too. I have learned much, and most of it has been from those fantastic kids who have the needs of any child, plus special individual ones. They keep teaching me how capable they really are and how to be more sensitive to everyone.

Suggested Readings:

Caring for Your Disabled Child by Benjamin Spock, M.D. and Marion Lerrigo, MacMillan Publishing Co., 1965. (Out of print - available in most libraries.)

What's the Difference? by Ellen Barnes, Carol Berrigan, and Douglas Biklen, Human Policy Press, Syracuse, NY, 1978.

Your Child's Self-Esteem by Dorothy Corkille Briggs, Dolphin Books, Garden City, NY, 1975.

Prepared by Jane Palmer, Special Education Teacher, Saint Albans, ME.

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Readings for Parents

No. 3

BUILDING YOUR CHILD'S SELF-ESTEEM

Self-esteem is feeling good about yourself. It is feeling that you are lovable and worthwhile.

Children with handicapping conditions gain self-esteem the same way "normal" children do - by having their needs met.

Earliest Needs

Building self-esteem starts as soon as the baby is born. Being cuddled and talked to meets needs which are as important as are food, clothing, and shelter.

Parents of a handicapped baby may have many confusing emotions, such as disappointment, sadness, concern for the child's future, resentment, or a sense of failure. This may make it difficult to give all the love messages a baby needs. These emotions are understandable and will take time to work through.

Sometimes parents find it hard to hold and snuggle their baby if the handicap is a physical one, or if the baby is unable to respond. If you have trouble holding your baby, try looking for what is beautiful and normal. Touch his fine skin. Look into his bright eyes. Let him curl tiny fingers around your big one. Talking, singing, and making sounds back are important too. Even if your baby is deaf, he will feel vibrations from your voice when you hold him.

As your child grows older, you will find she has her own special ways which you enjoy. Your love can give her the confidence she will need to handle whatever problems she must face.

Needs as a Family Member

Handicapped children need to feel they are a part of the family, just as the other children are. To feel this way, they need to be treated like the other children.

Your handicapped child needs to learn to do things for herself. She may not learn things as early or easily as your other children, but she needs to be given the chance.

She should be allowed to feed herself. If she spills, you can help her learn to clean up the spills. This will make her feel good about herself.

If your other children are expected to do chores, then your handicapped child should have a job too. She may not be able to mow the lawn, but how about sorting and folding the laundry? These things may take some special planning, but your effort will help her feel worthwhile and grow in self-esteem.

All children need to have special, individual attention. Your handicapped child may require even more. Each member of the family can help

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and, as a result, benefit from the relationships that will be formed. No one person will feel entirely responsible, and your other children are less likely to be jealous of the time you spend with your handicapped child.

It is important that your handicapped child have ways she can help other members of the family, too. Her self-esteem will suffer if she always receives help without giving in return. Perhaps she can keep the baby happy so you can have some time to yourself. Maybe she can read to a younger child, or help an older one learn his spelling.

Children continue to need touch and body closeness long after they are babies. Your handicapped child may be difficult to hold. If so, plan ways to include him in activities near you. Perhaps you can prop him in the corner of the couch close to you while you read a story to him and his sister. You can put an arm around him, help him turn pages and point to pictures. He will feel loved and wanted. His self-esteem will grow.

Having a clean, well cared for body is important to every person's self-esteem. Your handicapped child needs to feel good about his appearance and have pride in using his body to the best of his ability.

Because a handicapped child usually requires extra time and energy, it is wise to plan how you can use what you know about your family to avoid conflict. As a parent, you know what your children like and dislike. You know what they do well and what is hard for them. You know when they are likely to be cranky and when they probably will be cheerful.

Suppose four-year-old Johnny gets cranky about 3:00 o'clock if he doesn't have something to eat. You are often busy then and his whining makes you cross. He cries, and you both feel bad about yourselves.

Help yourself by planning ahead. You can have a sandwich and glass of juice or milk ready for Johnny to get for himself. Letting Johnny plan with you what he will eat, where he will eat it, and how to clean up afterward will show him you trust him. He will feel grown-up. You will be pleased with him and you will both feel better.

Needs Outside the Family

Your handicapped child needs to know about life outside the home. As often as possible, she should be included in grocery shopping, trips to parks, going to church, and visits to neighbors.

Handicapped children need to play with other children. You may need to find others to share the kind of play your

child can enjoy. It is important, however, for your child to play with non-handicapped children - this will help her understand that she is more like these children than she is different.

Your child needs to play with dirt, feel leaves, bark, branches, and walk in rain and snow. He needs to pet animals, watch birds, and see the moon and stars at night. If it is really impossible for your child to be outside to enjoy these things, then provide him with a sand tray, let him play in water in the tub or basin, and bring in snow for making small snowmen. Having indoor plants or a pet which he helps take care of teaches him responsibility.

All children need to have materials with which they can create while they play. Crayons, markers, paints, scissors, clay, building blocks, and tinker toys can be used to make what pleases him. He should not have to make things to please others. In this way, he can let go of tensions and relax. Creating what pleases us gives us a sense of well-being which helps build self-esteem.

As you strive to keep your family life as normal as possible, while meeting the needs of your handicapped child, you will find many ways to manage. Be proud of how well you do. Remember to find a little time each day to let go of your own tensions. In building your own self-esteem you also help build your child's.

Suggested Readings:

Caring for Your Disabled Child by Benjamin Spock, M.D. and Marion Lerrigo, MacMillan Publishing Co., 1965. (Out of print - available in most libraries.)

Nineteen Steps Up The Mountain - The Story of the DeBolt Family by Joseph P. Blank, Lippincott, 1976.

T.A. for Tots by Alvyn M. Freed, Jalmar Press, Inc., 6501 Elvas Ave., Sacramento, CA 95819, 1973.

What's the Difference? by Ellen Barnes, Carol Berrigan, and Douglas Biklen, Human Policy Press, Syracuse, NY, 1978.

Your Child's Self-Esteem by Dorothy Corkille Briggs, Dolphin Books, Garden City, NY, 1975.

Prepared by Jane Cook, Home Advisor, Special Education Teacher, Dennysville, ME.

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Readings for Parents

No. 4

FOSTERING INDEPENCENCE

From the time our children first reach out to pick up a toy by themselves and take their first steps without holding on to our hands, they are learning to become independent of us, their parents. Certainly they have far to go, but these activities are the very beginning.

As we watch our children grow, try new things, and have new experiences, we encourage them. Whenever they want to try something they haven't done before, our first concern is for their safety - will they get hurt? It is fairly easy to watch our children do such things as taking their first steps alone, even though we know they will risk a few falls and bumps. This is accepted as part of growing up. We pick them up when they fall, give them a hug and kiss, and tell them to try again. Without being consciously aware of it, we are fostering their independence from us.

We help our normal children learn to walk, talk, feed and dress themselves, and play outdoors without our ever-present, watchful eye. They accomplish these and other new skills through trying, failing, and trying again. When they get hurt or do not succeed the first time, we know they will make it. We tell them that in different ways at different times. The important fact is, unless something unusual happens, they will become independent adults.

This is not true when a handicap affects a child's physical, intellectual, or social development. Many obstacles alter the process a parent and child must work through to move towards independence. This process is often so complex that we may not be aware of all its aspects.

Every physical hurt that child experiences is felt by the parent - felt keenly and intensely, and even more deeply if the parent thinks that something he or she did caused their child's handicap. Parents may also feel the condemnation (whether real or imagined) of others for pushing their child to learn and accomplish, when even the small gains may cause hurt and frustration.

Some people believe that handicapped children and adults should be protected and kept safe, rather than permitted to take risks and achieve skills, as well as personal growth. This belief directly conflicts with our natural instincts to help our children learn and one day be independent of our support.

As the parent of a handicapped child, I spent many hours when my son was very young wondering about the future. Would he walk? Where would he go to school? Would he ever have a job and live away from home and my care? Until I could begin to sift through these thoughts and put some of them into perspective, I was too overwhelmed to be able to help my son

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toward some kind of independence.

I wanted someone to tell me exactly what to do, when to do it, and what the results would be. No one could do this. Only through talking with friends and other parents of children with handicaps, reading about similar problems faced by other families, learning more about myself and from my son, sharing in the mutual support of my family, and making many mistakes was I able to take a direction that was good for both of us.

First, I learned to tackle one problem at a time. If I spent too much time thinking about how far my son would go in school or if he would ever have a job, I could not effectively help him learn to hold a spoon and feed himself. It was a relief to find how much I could enjoy his success at grasping a spoon and independently eating part of his meal without choking.

Each time my son attempted something new, I struggled with the fear that he would be physically hurt and anxiety as to whether or not he could succeed at the new task. The next, more important step was for me to relax and not anticipate trouble.

How should parents foster independence in their handicapped children? It is helpful to scale down the concept.

For many of us, it means leaving our parents and successfully living and working apart from them. For others, it may mean something quite different. A handicapped child who learns to speak or communicate in some other way is able to make his needs and wants known. In this way, he has become independent. We must think about ways our children can be independent, even though some help may be needed throughout their lifetimes.

Focusing on our children's independent successes and the shared joy in their achievements gives us satisfaction. It also gives us energy to help them go on to reach whatever independence is possible for them. These steps are difficult and often painful for both parents and children. But when we share the excitement and pride of our children in their successes, it is worth it.

My son taught me much about the value of growth and discovery through direct experiences. I resisted this from time to time, but he taught me well. Once, fearing for his safety, I tried in vain to prevent him from going outside during a raging blizzard. When he came back into the house, he said it all - "I just wanted to see what it was like to be out in a blizzard. You see, I never did that before."

Suggested Readings:

A Difference in the Family by Helen Featherstone, Penguin Books, 1980.

The Exceptional Parent (6 issues a year), P.O. Box 4944, Manchester, NH 03108.

Helping the Handicapped Teenager Mature by Evelyn West Ayrault, Association Press, 291 Broadway, New York, NY 10007

So Your Child Has Cerebral Palsy by Gil S. Joel, University of New Mexico Press, Albuquerque, NM, 1975.

Prepared by Ruth P. Shook, Parent of a handicapped child, Program Director, Bangor, ME.

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Readings for Parents

No. 5

YOUR MARRIAGE

Your family works like a set of gears - as one turns, so do they all. If one is changed, the whole system must adapt. When a handicapped child is born, all family relationships are affected. One of these to feel particular stress is your marriage. This child can either bond or divide you as a couple. All too often, the pressures are so great that the latter happens. Why? And more importantly, what can you do about it if it's happening to you?

Of course, each family's experience is unique, but there are certain common factors. As the parents of a handicapped child, you are on OVERLOAD. Your child requires more time and energy than the "normal" child. Feeding may be difficult and time-consuming. Sleeping patterns may be irregular. Special therapies must be carried out daily.

There are countless decisions to make (evaluations, operations, programming) and appointments to keep (doctors, therapists, specialists). Financial pressures grow. You must consider burdensome issues such as long-term care or whether to have more children. On top of all this, there is the emotional drain of dealing with the pain, anger, guilt, and sadness.

Operating under these awesome conditions is difficult, to say the least. It can be even harder if husband and wife see and handle the problems differently, thereby creating a potential for conflict.

Traditional roles for men and women teach different ways of coping, which can cause further stress. "She's always falling apart," "He acts like nothing is wrong," or "He won't talk about it." Disagreement occurs, then resentment and blame. At a time when support is needed, each spouse begins to shut the other out. Soon you may have a marriage in serious jeopardy.

What do you do?

1. Give yourself permission to focus on your marriage. Put a premium value on your marriage without feeling guilty. Focus time and energy there. Plan time away for the two of you alone. Making this marriage work will benefit your entire family.

2. Try to understand each other's feelings. Recognize that the issues are different for each of you. Try to understand, even if you can't always relate. Men have problems with self-esteem, guilt, financial worries, or having to appear strong and tough. Women tend to feel guilty, blame themselves, and need to express their feelings.

3. Communicate. Listen to each other and respect your differences. Don't censure and judge. Talk before you feel explosive - even if it feels like work.

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4. Share your heartaches and joys. Turn to each other first. Use family and friends as secondary support systems.

5. Share your child. Remember you both can give this child care and love. Don't let it fall primarily to one.

6. Join a group of parents of handicapped children. There's nothing quite like the understanding of someone who is experiencing the same thing you are. You BOTH need to find this support.

7. Consider counseling. Reaching out for professional help doesn't mean you're weak or a failure. It means you're smart to see that something else could help, and you're brave enough to try!

Remember, your own well-being and that of your marriage is the best gift you can give to your child!

Suggested Readings:

A Difference in the Family: Life With a Disabled Child by Helen Featherstone, Penguin Books, 1980.

A Handicapped Child in the Family: A Guide for Parents by Verda Heisler, Grune & Stratton, 1972.

Listen to Your Heart: A Message to Parents of Handicapped Children by Elise H. Wentworth, Houghton Mifflin, 1974.

Raising the Exceptional Child: Meeting the Everyday Challenges of the Handicapped or Retarded Child by Lawrence Zuckerman and Michael Yura, Hawthorn, 1979.

The Special Child Handbook by Joan McNamara and Bernard McNamara, Hawthorn, 1978.

Prepared by Kristine Zuckerman, Counselor (specializing in work with families of handicapped children), Portland, ME.

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No. 6

THE SINGLE PARENT

How often have you heard someone say that being a parent is the hardest job they've ever had? It's true, and it's fair to say that parenting a handicapped child is doing double duty - more worries, more decisions, and more caretaking tasks. If you are a single parent, you are certainly justified in feeling overwhelmed. You've been handed the tough job of working the day and night shifts with no vacation time and no co-workers to help you solve problems.

The most common problem for the single parent of a handicapped child is over-involvement. You may concentrate too much energy on him or her for many reasons. Often there are feelings of guilt at being the "only" parent. So, you try to be both father and mother. Other times there is no other diversion from the loneliness of being single. What gets lost in all this are your own needs and identity, as well as the child's potential for independence. These losses can cause serious problems later.

How can you change this? The key is your attitude. Yes, your child needs you and should be able to count on you for many things in terms of care and security. Martydom is not one. You are a person, entitled to your own separate life. You do not need to feel guilty about seeking fulfillment and happiness. On the contrary, if you are unhappy, you will not give your child a sense of well-being - one of the most important things you have to offer.

Here is an example: Suppose it's your daughter's bedtime. You have been stuck in the house all day and you're feeling stale and tired. You can't wait for the day to end. As a result you're irritated, you grumble, and hurry her along.

Now suppose you've been out during the day with a friend and have had some fun and a change. You feel cheerful and refreshed. You hum, tickle her toes, and laugh at her antics. Which mother (or father) is best for this child?

Once you give yourself permission to have your life, you've solved the major part of the problem. Now put energy into making things happen. Remember never to let yourself get away with saying, "I can't." That really translates, "I won't."

1. Create some support systems. Reach out to parent or church groups.

2. Rely on family and friends. Let your relatives, if near by, help you, but beware of becoming too dependent on them. It is especially important for you to find at least one other person to have a close relationship with the child.

3. Make time to be alone or with special friends. You can train responsible babysitters or, if this is a problem, arrange swapping systems with other parents.

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4. Have a healthy attitude about dating. When you feel ready, approach new relationships with the opposite sex. Don't regard every date as a potential spouse. Otherwise, you may get bogged down with such questions as "Will he accept the handicap?" or "How shall I explain it to her?" If you are relaxed about your child, this will be contagious. If things do begin to get serious, remember that your own acceptance and understanding didn't come overnight. Don't be disappointed or angry if someone isn't quite sure how to handle the situation. Give things time.

Yes, your child is dependent upon you for love and nurturing. While you do your best for him or her, remember also to leave space for each of you to develop separate identities. In this way both of you can find happiness.

Suggested Readings:

A Difference in the Family: Life With a Disabled Child by Helen Featherstone, Penguin Books, 1980.

Listen to Your Heart: A Message to Parents of Handicapped Children by Elise H. Wentworth, Houghton Mifflin, 1974.

MOMMA, The Sourcebook for Single Mothers, Edited by Karol Hope and Nancy Young, New American Library, 1976.

Raising the Exceptional Child: Meeting the Everyday Challenges of the Handicapped or Retarded Child by Lawrence Zuckerman and Michael Yura, Hawthorn, 1979.

Self-Esteem Is a Family Affair by Jean Illsley Clarke, Winston Press, Inc., 1978.

Prepared by Kristine Zuckerman, Counselor (specializing in work with families of handicapped children), Portland, ME.

A Handicapped Child in the Family

Readings for Parents

No. 7

SIBLINGS

Siblings of handicapped children experience a range of feelings, just as their parents do - love, anger, appreciation, or loneliness. Sometimes they are embarrassed around their friends; sometimes they are proud of the accomplishments of their brother or sister. Many children become very parental toward their handicapped sibling at a surprisingly early age. Often they learn compassion for others who are different.

Some may be bitter and ask, "Why me?" or "Why us?" They may worry about whether or not they will have a handicapped child when they become parents. They also may wonder and worry about their responsibilities for the handicapped brother or sister when they are all adults. Often these children are silent about their emotions.

Accepting Your Child's Feelings

None of these feelings can be prevented. They are all realistic responses to the experience of having a handicapped sibling. They are not good or bad - they exist. The important thing is to encourage your child to express these feelings and then to accept them, to feel comfortable with them. Hiding them hinders growth. If emotions are not expressed, they can cause children to become depressed or angry.

Guilty Feelings

Siblings of handicapped children usually experience guilt. Some feel that they should have been the one afflicted. Others may feel that they caused the handicap. Of course this is not logical, but our feelings don't follow logical patterns.

Mostly, children feel guilty for having so-called "negative" feelings toward their sibling who is handicapped. They think that they must be terrible to wish they never had such a brother or sister, or that the handicapped child would die. They also feel guilty for wanting more attention than the handicapped sibling. At times, they are resentful of the attention that this brother or sister gets and the restrictions placed on the whole family because one member is handicapped.

Again, if these very normal feelings are not expressed, there may be negative effects on the child who is experiencing them, and on the family. The child may think that it is the feelings themselves that are bad, rather than realizing that it is the suppression of feelings and the isolation that hurt so much. This happens to all of us, young and old. Sometimes children become despondent, do poorly in school, or begin getting in trouble as expressions of these internal difficulties. It is important for us as parents and professionals to be on the lookout for these signs of conflict.

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The Importance of Independence

Another area of concern is that siblings of handicapped children are often overprotective. They don't like to see their brother or sister struggling and often failing. They experience pain from these situations. They think that "it's not fair." Perhaps they are right. But fairness is not the point. Learning to be as independent as one can be is the point. That involves pain because it involves growth. Certainly in the short run, it's a lot easier to do something for someone you love, but ultimately it can be damaging. It can cause intensely ambivalent feelings between siblings. Of course this is an area in which children learn best by the example of the adults around them.

Helping Our Children Cope

As parents, we can be of most help to our children by being honest with ourselves about our own feelings. Once we can do this, we are more likely to recognize similar feelings in our children and set the kind of example from which they can learn.

We can also help our children to use their senses of humor as a coping device. Sometimes kids feel that they are being cruel or insensitive when they see humor in a situation involving their handicapped sibling. They confuse "laughing at" with having a sense of humor, and may feel guilty about their "laughing" feelings.

Primarily, it is important to listen and to understand your children's feelings. This can be painful, but also enriching. Rather than experiencing only the burdens of having a handicapped sibling, a child in these special circumstances can be helped to learn and grow.

Suggested Readings:

A Difference in the Family by Helen Featherstone, Penguin Books, 1980.

A Reader's Guide - For Parents of Children with Mental, Physical, or Emotional Disabilities, U.S. Department of Health, Education, and Welfare, 1979. (For sale by Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402, Stock No. 017-026-000-58-5.)

The Special Child Handbook by Joan McNamara and Bernard McNamara, Hawthorn, 1978.

Prepared by Robert M. Keteyian, Child and Family Therapist, Mental Health Consultant, Ellsworth, ME.

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Readings for Parents

No. 8

CHANGES IN FAMILY LIFE

You have just arrived home from the hospital with your newborn. Usually this is a joyous occasion, but for you, the parent of a handicapped child, it's one of anxiety and fear that something could go wrong at any moment. Suddenly, without warning, your life has taken an abrupt turn and you are facing an unknown future with your child. Often, it is the unknown that causes people to be afraid.

You find yourself in a new role with no script but plenty of racing thoughts and feelings. It's natural for you to wonder just what your life, and those of your spouse and other children, will be like in the future. All your hopes and dreams of raising a "normal" child with the usual fanfare of birthday parties, school days, adolescence, and marriage have been dealt a critical blow. And what about you? Your hopes and dreams? Your future plans and those of your spouse?

Changes occur in everyone's life. How you view your situation will determine how meaningful and positive your family's lifestyle will be. The only way to pursue your new lifestyle is to accept your circumstances just the way they are. Your life will take on a new and different meaning, but the road has been traveled before by people who can be helpful to you right now, right where you are, Reach out to others and gain support, as well as ideas and information about where to go from here.

Some parents have found a new career in helping others with similar problems by entering the fields of education, counseling, therapy, medicine, or research. Others have started parent groups or other support systems.

I was so grateful for the help and support I got from various resource people and friends that, with their aid, I turned my "dilemma" into a career. The knowledge I gained from working with my child and the many professionals involved gave me the confidence to take courses at a nearby university. This lead to a job helping other parents cope and work with their handicapped children.

Not everyone is free to do this, but those who have gone through the pain can offer that "special" insight that comforts. At the same time, their own strength to carry on is renewed.

Does It Have to Be So Different?

The birth of any baby will cause changes in a family's routine. Most families have made the necessary preparations to help things flow smoothly by the time the baby comes.

With a handicapped child, the same preparation is needed. The difference lies in the added extras of his or her care. These may include:

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1. gaining knowledge from trained professionals as to the care and handling of your child. Don't be afraid to ask questions. Jot down all your questions beforehand to insure nothing is forgotten. Before you leave the hospital or doctor's office, be sure they have all been answered.

2. locating a support and/or parent group which can help you deal with your particular needs as parents, spouses, siblings, and grandparents. All parents have ups and downs when it comes to raising a child. A baby who places added demands may cause you to feel overburdened.

3. deciding how to tell other family members about your child's handicap and stating your expectations, if any, for their help. Be sure to give siblings accurate information from the start. Your pediatrician can give you advice. Often what small children imagine is far worse than the reality. As for other close relatives, you may get "peculiar" reactions. Don't let this alarm you. They, too, are trying to find ways to cope with a "difference" in their family. Although their adjustments may seem minor compared to yours, they too are facing a totally new situation.

4. taking stock of your finances to see what supplemental income you may need to cover the additional medical or professional costs. Have your doctor refer you to programs which may be able to help.

5. looking closely at the space you've set aside in your home for your child. Decide if it's suited to his or her needs and make necessary adjustments. You may need extra space for equipment for your child's therapy or care.

6. determining the amount of extra care your child may require. Try not to shortchange the other priorities in your life - spouse, siblings, friends, community, and work. Don't be afraid to ask for help!

7. coping with the unexpected changes in your daily routine. As my child's resistance to respiratory infections was low, she was very susceptible to colds and flu. Often what would start out as a common cold would turn into a nightmare of doctor's visits or a hospital stay. Often I had to ask a friend to help me through. I learned to get extra rest whenever possible, and let trivial matters, such as housework, go. Also, I learned to call on people whom I knew would be understanding - therapists or other parents of handicapped children.

You Do Have A Choice

The decisions you make now about your life and that of your child can help you focus on positive, as well as effective, changes -- changes that will touch the lives of others as well. Remember -- you are not alone!

Suggested Readings:

A Difference in the Family by Helen Featherstone, Penguin Books, 1980.

A Handicapped Child in the Family: A Guide for Parents by Verda Heisler, Grune & Stratton, 1972.

A Reader's Guide - For Parents of Children With Mental, Physical, or Emotional Disabilities, U.S. Department of Health, Education, and Welfare, 1979. (For sale by Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402, Stock No. 017-026-000-58-5.)

The Special Child Handbook by Joan McNamara and Bernard McNamara, Hawthorn, 1978.

Prepared by Cheryl Fernald, Parent of a handicapped child, Home Advisor, Machias, ME.

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Readings for Parents

No. 9

COPING

Being the parent of a handicapped child can be demanding, lonely and frustrating. It can be hard to listen to the "professionals" who may tell you, "Let's wait and see how your child develops," "Things aren't so bad," or "You're lucky your child's defect is not so apparent." Having a family and friends who may deny a problem exists, or try to make things be what they are not, can make it even more difficult for you to get the necessary emotional support for raising your handicapped child.

Learning how to cope with intense feelings and day-to-day living, as well as each new situation which arises for your child, is not easy. Parents find many different ways to cope. Following are suggestions which have worked for other parents:

1. Acknowledgement that a problem exists is the beginning. The doctor's office is often where a problem is first detected. When your doctor listens and responds to your fears or concerns, you can start to deal with them. As one mother described it, "When a doctor agreed that there was a problem with my son's development, my concerns were validated. I learned that I could be assertive, that I was not simply being over-protective." It makes you feel stronger if someone agrees there is reason for concern. Then you can act.

2. Learn how to ask for help for both you and your child. To get services you need to learn to speak up. Many parents find this very difficult. Start by asking your doctor or human services agencies.

3. Trust others to become involved with your child. It will help you cope with new situations. For instance, if your child is in preschool, the adults in that program want to share with you the joys and new accomplishments, as well as regressions or defeats. You need others who understand and can speak for your child.

4. Find support from people who have gone through a similar experience. A parent support group can give you strength. Listening to others tell of their successes helps you learn how to make your needs known. Such a group can help you find necessary resources and services.

5. Counseling can be useful. It can help partners maintain their relationships with each other, their child and other siblings. Not all parents feel the need for counseling. For them, it is important to reach out, to be able to talk to someone with experience. Trying to cope "on your own" can be both frightening and defeating.

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6. Find someone, a partner, family member, or close friend, to count on. Take someone with you when you go for an evaluation or a visit to the doctor with your child. Just having the physical presence of a friend can be very supportive for you.

7. Respite care is essential. Allowing yourself to take a break and do something just for yourself will benefit both you and your child in the long run. In many areas you will find agencies or organizations that provide respite care for families with special needs. Often a church can put you in touch with someone who will give you a break and care for your child for a day or an evening. Turn to your family or friends to babysit for you. Do it regularly.

Two questions are asked by parents time and time again. "Am I doing the right thing for my child?" and "Have I done enough?" It is important to realize that other parents have similar concerns, and to find out how they cope with the difficulties of raising a handicapped child. Each family is unique and has its own needs. Ways of coping are different for each parent, but listening to others will help you find your own solutions.

Suggested Readings:

A Difference in the Family by Helen Featherstone, Penguin Books, NY, 1981.

"The Lonely Search for Help" by Diane Kovacs, The Exceptional Parent, April/May, 1972.

New Directions for Parents of Persons Who Are Retarded by Robert Perske, Abingdon Cooperative Publication Association, Nashville, TN, 1972.

Prepared by Anne Chaisson, Social Worker, South Portland, ME and members of the York County Parent Awareness Group, York County, ME.

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Readings for Parents

No. 10

REACTIONS OF OTHERS

There are three basic negative reactions people have to children with obvious physical or mental problems: pity, false cheerfulness, and withdrawal. When your child was born or diagnosed, you may have had similar feelings.

Even before you learn to be secure within yourself, you will probably have to face the adverse reactions of others.

Your parents: They are now grandparents. You may feel you will surely receive help and encouragement from them, only to find the reverse is true. How will you respond to an unthinking, cutting remark, a refusal to hold your child, or a "smothering" of the child - not allowing him to do what he can?

Friends: Your closest friend suddenly doesn't come over or call. She tells mutual friends that she is afraid to look at, be near, or touch your child. Others imply that this happened to you because of some physical defect. They do not realize that it could happen to them.

Strangers: In the doctor's office or the supermarket you hear whispers: "What a pity." "Such a shame."

How do you protect yourself and your baby from such reactions? How do you handle the feelings of anger and sorrow? You will eventually find answers to these problems on your own. Not everyone has these negative reactions, and you will find help and strength in unexpected places and people.

When you accepted this child's handicap, you put yourself on her side. You became her helper and champion. There are people ready and willing to assist you. The professional people you meet deal with many problems and many children. There are also parents who have been through this already and are willing to share and help.

The acceptance and awareness of others is something to work for. The normal reaction of people is, "Thank God it wasn't my child." Everyone needs to realize, "It could have been."

Here are some ways to help others understand:

1. Try to explain your child's condition. You tell them. They may never ask. Your child may be able to do the same.

2. Discuss any negative reactions with professional people - your doctor or therapist. Ask them for suggestions. They deal with many situations, while you see only one.

3. Volunteer written information to people - pamphlets and booklets that can help your friends and relatives see that yours is not an isolated case, and that you are doing what is needed for your child.

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4. Point out things your child has in common with others - abilities and feelings. Likenesses will outnumber the differences. Give people a chance to interact in positive ways with your child.

5. Emphasize your child's strengths. Say, "We are fortunate because our son can _____!"

6. Suggest that others "try on the handicap," and experience the frustrations of the handicapped child. Books are available with suggestions which may help you do this.

Suggested Readings:

A Difference in the Family by Helen Featherstone, Penguin Books, 1980.

Caring for Your Disabled Child by Benjamin Spock, M.D. and Marion Lerrigo, MacMillan Publishing Co., 1975. (Out of print - available in most libraries).

Living Fully: A Guide for Young People With a Handicap, Their Parents, Their Teachers, and Professionals by Sol Gordon, John Day, 666 5th Ave., New York, NY 10003, 1975.

What's the Difference? by Ellen Barnes, Carol Berrigan, and Douglas Biklen, Human Policy Press, Syracuse, NY, 1978.

Your Handicap -- Don't Let It Handicap You by Sarah Splaver, Julian Messner, West 39th Street, New York, NY 10018, 1974.

Prepared by Ellie Crowley, Parent of a handicapped child, Steuben, ME.

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Readings for Parents

No. 11

DEALING WITH PROFESSIONALS

Professionals come in various shapes and sizes and are categorized, in the yellow pages that is, according to the special label they possess - pediatrician, psychologist, therapist, specialist, or educator. The list is endless. As parents of a handicapped child, you face an often confusing array of specially trained, hopefully competent professionals who, whether they recognize it or not, have you at their mercy. Their very words can either give you the sustenance to "carry on," or leave you in a devastated, helpless state. Pleasant, caring, and understanding professionals add sunshine to any client's day and, believe me, it's rarely forgotten.

Encounters With the "Doctor"

I remember sitting across the desk from a pediatrician, trying desperately to bring order to all the questions and emotions tumbling around in my mind. With each encounter, I felt more ill at ease and this blocked the flow of communication. Looking back, I can clearly see what was happening. Anyone who stares at the desk, the ceiling, or the floor makes you wonder if he's really listening, or if he really cares about your particular needs.

My contact with another of the numerous pediatricians we saw was always positive. He liked my child - apart from the fact she was "special." He took the time to play with her and to ask me about other areas of my life. This told me that he cared about me as a person. He gave me practical advice on the care of my child and, when he was uncertain about the next step, would refer us to other well-qualified resource people. All of these ingredients made a wealth of difference in my ability to cope with my handicapped child.

Helpful Tips

A lot of variables go into making visits and work sessions with professionals successful. It depends as much on you, as it does them - your own awareness and attitude. Your child's future is at stake, and you can make a difference!

Here are a few tips for dealing with the "professionals" in your life:

1. Well before your scheduled appointment, write down your concerns and questions. It's frustrating to be half way home from a visit and realize you forgot to discuss an important issue.

2. Be informed about your child's handicap. There are many books, articles, and brochures which cover just about any handicapping condition. The more you know, the easier it will be for you to discuss and understand matters relating to your child. Also, you'll be more confident!

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3. Make sure each professional working with your child is aware of the involvement of others. Coordination will prevent confusion or duplication, and also provide the best possible program for your child.

4. If you are not pleased with the results of your child's program, let the professional know how you feel. A competent and concerned professional will want to do all he or she can to correct a situation. At the same time, try not to expect too much. Professionals are specially trained people, but they are not magicians.

5. Frequently, appointments may be unsatisfactory. Perhaps you are too often rushed through a visit, do not get adequate answers to your questions, or thoughtless remarks are made. If these problems continue, inquire about other resource people in that field. Your child will benefit in the long run.

6. Learn about the various community and statewide groups which lend support to parents of handicapped children. These groups can help you cope with difficult situations, and find available resources.

7. Get a copy of the law describing your state's responsibility to provide an appropriate education for your child. Also, ask for a copy of parents' rights and the proper procedure for a P.E.T. (Pupil Evaluation Team), so you will be prepared to work effectively with the schools.

8. Finally, if a professional is giving excellent service to you and your child, be sure to let him or her know. Your warm smile and friendly conversation just may give them the special "lift" they needed that day. As a professional and a parent of a handicapped child, I know how important this is.

Suggested Readings:

The Assertive Option - Your Rights and Responsibilities by Patricia Jakubowski and Arthur J. Lange, Research Press Company, 1978.

Doctor & Child by T. Berry Braselton, Delacorte Press, 1970.

The Exceptional Parent (6 issues a year), P.O. Box 4944, Manchester, NH 03108.

Prepared by Cheryl Fernald, Parent of a handicapped child, Home Advisor, Machias, ME.

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Readings for Parents

No. 12

PARENT-PROFESSIONAL RELATIONSHIPS

Communicating

Mutual self-respect is critical for parents and professionals in dealing with each other. In most cases, parents have children because they want to care for them; most professionals chose working with children because they want to care for them. Each has information and skills that the other needs to be "successful." It often looks to parents as though outsiders hold the child's future in their hands. For their part, professionals often feel far less powerful than they appear to "clients."

Assertiveness

Parents may need to insist on being recognized in their dealings with professionals. After all, most professionals have credentials that imply they know what they're doing. Parents need to show in positive ways that they also know what they're doing. Parents need to ask questions. They're not expected to know everything that it may have taken the professionals several years to learn about. Don't hesitate -- ASK!!

Professionals "Say The Darndest Things"

Each profession has its own language. For the parent, this may be like traveling to a foreign country. Even common, everyday words may mean one thing to parents and another to professionals. At times, professionals may try to avoid confusing the parents by using terms they think will be understood - such as, "your child will never be college material, but he'll do all right." All the parents wanted to know was why their child couldn't talk better. Keep asking questions. Ask the professional to clarify what he means - even when you may not want to hear the answers. Remember that it is also hard for the professional who must give parents answers that are sometimes very painful.

Making Sense of What Everyone's Telling You

One of the most common complaints that parents have is: "How am I expected to know what to do when I get opposite opinions from the people who are the experts?" Parents need to consider all the information, ask the professional with whom they're most at ease to help sort it out, and then decide for themselves what's best for their child. It's not easy, but it's well worth it. It's your child's whole future!

Suggested Readings:

A Difference in the Family by Helen Featherstone, Penguin Books, 1980.

The Assertive Option - Your Rights and Responsibilities by Patricia Jakubowski and Arthur J. Lange, Research Press Company, 1978.

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The Exceptional Parent (6 issues a year), P.O. Box 4944, Manchester, NH 03108.

Prepared by Margaret I. Bruns,
Program Director, South Portland, ME.

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Readings for Parents

No. 13

YOUR CHILD'S EDUCATION

As your child with special needs approaches entry into public school, you may feel anxious and uncertain. When you go to the school to talk about your child and his handicapping condition, your own school memories and experiences, as well as concern for your child may make it difficult for you to feel relaxed. Today's schools, however, are much more open and child-centered. They are places where students and parents can feel at ease.

When your special child is three years old, it is not too early to let the school know about her. By the time your child is four, you should have informed the school that you have a child who needs special consideration.

A call to the principal of the local elementary school is the best way to begin. He will probably be very interested in learning about your son or daughter and may arrange a home visit by the school nurse, the special education or kindergarten teacher. Later, the school will arrange for a meeting to talk in detail about your child's program.

All too often, parents of handicapped children approach the school expecting that they will have to fight to obtain services for their youngster. They sometimes think that the school will not provide proper programs unless it is forced to do so. My experience has shown that teachers and administrators are willing to do everything in their power to provide the best education for students with special needs. They are almost always eager to do what the parent wishes.

One of the reasons for this willingness is that, as a society, we have begun to accept our handicapped citizens and to respect the contribution they make to us all. The schools reflect this good will and have made great progress away from the neglect and isolation of handicapped children in the past. Another powerful reason is of course "The Education of All Handicapped Children Act" (PL 94-142), which states exactly the kinds of services which schools must provide for special students.

One of the provisions of this law is that each school has to have a Pupil Evaluation Team (P.E.T.). This team recommends evaluations for handicapped students, decides where the child should be placed, and draws up an individual education plan (I.E.P.) for each handicapped child.

A P.E.T. may be large or small depending on the school. Usually, the principal, a teacher, special educator, and speech clinician or guidance counselor are on this team. The parents of the special child are also members and play a very important role in its decisions. The number of people on a P.E.T. can vary from five or six to as many as twelve or fourteen. The meetings may be formal and highly

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structured or informal and more like friendly conversations, often depending on the size of the school or district.

A large team meeting can be intimidating and keep you from speaking openly. You may want to bring a support person to the meeting - a friend, family member, or someone from a pre-school program if your child is involved in one. Whatever the size of the P.E.T., the intent is the same: to decide the best placement and services for the child.

Frequently, more than one meeting is necessary before concrete plans are made. The first meeting may be held to decide upon evaluations needed or steps to be taken.

School personnel look to the parents as the people who know more than anyone else about their child. They want parents' opinions about any proposed plan for the child's education. If you do not agree with the plan, the law calls for a series of hearings to resolve questions concerning placement and services. You also have the right to ask for an independent evaluation of your child.

If schools do not provide services which a child needs, there are usually two reasons: lack of money or lack of access to the service. Rural schools, particularly, find it difficult to provide occupational or physical therapy services for students, even though they know they are necessary. If direct service is not possible, the school may be able to arrange for a therapist to consult on a regular basis with the child's teacher and show her how to do the child's daily exercises. The therapy might also be delivered at home by an itinerant therapist, or after school at a clinic or hospital.

The school staff may suggest several possible placements for the child in school. Parents and the school should be flexible and creative about these choices. For example, a child with a speech problem may be able to attend a regular kindergarten and go to speech therapy sessions three times a week. A developmentally delayed child might be able to attend kindergarten for half the day, spending the other half in a pre-school setting. Another plan might be some combination of kindergarten and individual work in the resource room. Sometimes a physically handicapped youngster can function well in a kindergarten with a teacher aide or special teacher assigned to him or her for part or all of the school day. Other choices may be placement in a special class or school. A less frequent, but sometimes necessary, setting may be in a residential school, often many miles from home.

You should come to P.E.T. meetings prepared to state what you will and will not accept for your child. The important issue is how you, the parents, feel about each possible placement discussed. If you are not ready to decide, you should say so and ask for more information or time. When a decision is reached, you will be asked to sign a statement that you agree with the placement and the educational plan for your child.

It is important that you are prepared for your role as members of the P.E.T. Talk to parents of older handicapped children, as well as pre-school teachers and therapists who know your child and the programs that are available. Visiting programs in the area and observing teachers and handicapped students can help you decide if a setting is right for your youngster. In some cases, bringing your child with you will help you get a feeling for which program is appropriate.

If you know what you want for your child when you approach the school and are persistent in making your opinions known, you can have an enormous influence on the school staff. When you work with school personnel as a team, even in the face of reduced budgets and personnel, your youngster will benefit. You will receive support in the difficult task of raising your handicapped child, and the school will be proud to have met its responsibility for educating all of its children.

Suggested Readings:

A Primer on Due Process: Education Decisions for Handicapped Children by Alan Abeson, Nancy Bolick, and Jayne Hass, Council for Exceptional Children, 1975.

The Assertive Option - Your Rights and Responsibilities by Patricia Jakubowski and Arthur J. Lange, Research Press Company, 1978.

The Exceptional Parent (6 issues a year), P.O. Box 4944, Manchester, NH 03108.

Parents - You're Part of the Team by Cyril J. Leise, Director, Direction Services, Meyer Children's Rehabilitation Institutes, 444 South 44th Street, Omaha, NE 68131.

The Right of Handicapped Students to an Education - Primer 1, Seeing the I.E.P. Through the Eyes of a Parent - Primer 2, Procedural Safeguards: What, Why, and When? - Primer 3 by Dorothy McNair and Bodie Smith, Exceptional Family Advocacy Center, Center on Human Development, University of Oregon, 1590 Willamette Street, Eugene, OR 94701.

Prepared by Rosemary Babcock, Parent of a handicapped child, Program Co-ordinator, Brewer, ME.

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Readings for Parents

No. 14

EARLY INTERVENTION

The most dramatic growth and development in children takes place during the first five years of life. This is an especially critical period for children with handicaps or delayed development. Help for children during these formative months and years can make a significant difference in a child's overall growth and development. This is what early intervention is all about.

A few years ago, it was not uncommon for parents seeking professional advice about their handicapped child to be told to wait awhile, even until the age of four or five, before beginning any special training or therapies. More recently, medical, educational and child development people are encouraging families to begin developmentally appropriate activities as soon as a delay or handicap has been identified. **Early intervention can prevent** serious problems from developing later in a child's life.

Parents are the most important component in their child's program of early intervention. Certainly, the skills and knowledge of doctors, therapists, teachers and others are necessary in determining the appropriate intervention program for children, but it is the parents who will be working on these activities regularly with them. Parents and professionals working together make an unbeatable team.

There are different models or types of early intervention programs:

1. home-based, with child development or other workers making home visits, evaluating the child, setting up an individual program plan, working on the activities with the child and teaching families how to carry out the activities between worker visits.

2. center-based, with parents taking their child to a center or a central location for group and/or individual activities.

3. a combination home and center-based program.

Parent meetings and training sessions are an integral part of all early intervention programs. These provide opportunities for parents to learn more about their children, as well as to help each other in finding solutions to difficult situations they face in raising their developmentally disabled child.

Suggested Readings:

The Baby Exercise Book by Dr. Janine Levy, Pantheon Books, a division of Random House, Inc., New York, 1974.

Handling the Young Cerebral Palsied Child at Home by Nancy R. Finnie, E.P. Dutton and Company, 201 Park Avenue South, New York, NY 10003, 1975.

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Infants & Mothers by T. Berry Brazelton, M.D., Dell Publishing Co., Inc., New York, 1969.

The Magic Years by Selma H. Fraiberg, Charles Scribner's Sons, New York, 1959.

Toddlers & Parents by T. Berry Brazelton, M.D., Dell Publishing Co., Inc., New York, 1974.

Zero to Three - Bulletin of the National Center for Clinical Infant Programs, 733 15th Street, N.W., Suite 912, Washington, D.C. 20005.

Prepared by Ruth P. Shook, Parent of a handicapped child, Program Director, Bangor, ME.

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Readings for Parents

No. 15

USE & MISUSE OF LABELS

To Know or Not to Know

Raising happy, healthy, well-adjusted children is quite a task, regardless of a child's needs. But what if you have a nagging feeling that something is wrong with your baby? Your infant's pediatrician, your friends, even your spouse, try to reassure and convince you that: "He's fine," "There's nothing to worry about," "He's only a slow starter and will outgrow the delay soon enough," or "Stop being a hysterical parent!" Yet, this feeling never really leaves you.

New parents may naturally feel worried and concerned, but if your child is slow to respond or doesn't move or grow like other children, worries mount. Denying your feelings doesn't eliminate them and only adds to the frustrations and demands of parenthood. Resentments and feelings of inadequacy are often a result. All babies take a lot of time and energy. If your child has a problem, much of your energy is spent worrying, leaving little left for daily baby care.

If you are convinced from your own observations that something is wrong, take action. Start with your pediatrician. Be prepared to specifically explain your concerns and questions. After your child has a thorough physical examination, your doctor should be able to recommend a specialist who can do more detailed assessments.

Rely on your doctor or a recommended professional to coordinate the evaluations and explain reports and results.

When a diagnosis is made, it is sometimes a source of relief for parents. It puts a label on your child's problem and justifies your feelings. It allows you to go through the "mourning process." Later, with help, it allows you to understand your child's needs and begin to meet them.

If your child's handicap is diagnosed at birth, you may go through the "grieving process" sooner. However, there is also the risk of short-changing your baby by expecting less of his/her development. If these low expectations are shared by others, friends and professionals, a positive parent-child relationship is interrupted. More emphasis is placed on the handicapping condition, than on the child and his/her abilities.

A child's identity can easily get lost in a disability. Even the words used to describe a problem reflect the often automatic labelling that takes place. We hear the "Down's Syndrome child," rather than the "child with Down's Syndrome."

Summary

It is important to realize that the diagnosis of a handicapping condition is not the final word about a child. It does not predict what a child is

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capable of doing in his life, or what potential can be nurtured through early intervention and education.

Labels can be useful, but they are often misused. This can be avoided by remembering that a child with a disability is still a child. Although his or her needs may be greater at times, they are not much different from those of all children.

Suggested Readings:

Children with Handicaps, A Medical Primer by Mark Batshaw, M.D. and Yvonne Perrit, Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21204, 1981.

Issues in the Classification of Children: A Sourcebook on Categories, Labels and Their Consequences, edited by Nicholas Hobbs, Jossey-Bass Publishers, 615 Montgomery St., San Francisco, CA 94111, 1975.

One Step at a Time, Closer Look, Box 1492, Washington, DC 20012.

Prepared by Linda Labas, Early Childhood Specialist, Bangor, ME.

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Readings for Parents

No. 16

THERAPISTS AND THEIR WORK

The Speech & Language Pathologist

Many people wonder: What does a speech and language pathologist (SLP) do with a child from birth to five years old? What is the difference between speech and language? What is a pathologist?

"Speech" refers to the sounds that we use to talk and their quality. "Language" refers to our choice and use of words, their meaning and understanding, and the grammar of word combinations. "Pathologist" means one who studies the nature and cause of disease or, in this case, abnormal speech and language. Speech and language pathologists are also called clinicians or therapists.

The SLP wants to know if a child is developing normally in the following areas: feeding, making sounds, listening, saying and putting words together, understanding what is said, speaking clearly, and talking fluently.

These are all building blocks in developing good speech and language. Early diagnosis of problems, and treatment in these areas, can help a child to reach his/her potential.

A diagnosis (definition of the problem) is reached by a variety of procedures. Each child's strengths and weaknesses are assessed. The "tests" used are actually games enjoyed by children and parents alike.

If a child is diagnosed as having a specific speech and/or language problem, therapy is usually recommended. What does this involve? While the child sees therapy sessions as playful and entertaining, using toys, books, picture cards, and songs, the SLP has specific learning goals in mind.

Parents are important speech and language models for their children. Teamed with the SLP, they participate in therapy sessions and do carry-over activities on a daily basis.

Physical and Occupational Therapists

Who?

Physical or Occupational Therapists (PT and OT) specialize in observing, assessing, and developing a child's ability to move. They attend four years of college and then complete supervised internships in working with children or adults.

What?

Children learn to move by doing just that - moving in a variety of ways. Movement can be looked at in terms of gross and fine motor skills. "Gross" motor skills are total body movements, such as sitting or standing. They are the foundation for fine motor skills, such as the use of hands/fingers and the mouth (for eating and speech). All of these require balance and coordination, another focus of the therapist.

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These skills are also the basis for much of our later learning in school and life. For example, learning shapes, letters, numbers, and self-care activities (dressing, eating, etc.) requires that the body, eyes, and hands work together well.

Sometimes a child is slow in his or her development or had problems at birth that can affect movement. With the help of a PT or OT, parents learn to encourage their child to move in ways that will develop the skills necessary for rolling, sitting, crawling, standing, and walking. The OT or PT will use play and a child's normal body movements in therapy. It's important that therapy be fun for a child. In this way, it will become part of the child's daily life.

Where and When?

An OT or PT may work in the hospital, home, or school. If possible, the therapist and doctor should begin working together when a child is three or four months old. It is in the first five years that the most dramatic development in children takes place.

PT or OT - What's the Difference?

In terms of work with children, the professions of OT and PT can be interchangeable, depending on the therapist's experience. The traditional definitions are no longer adequate - your child may work successfully with either an OT or a PT at any given time.

Suggested Readings:

Children with Handicaps, a Medical Primer by Mark Batshaw, M.D. and Yvonne Perrit, Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21204, 1981.

The Exceptional Parent (6 issues a year), P.O. Box 4944, Manchester, NH 03108.

Help For the Handicapped Child by Florence Weiner, McGraw-Hill, 1973.

Your Child's Speech by Flora Schreiber, Ballantine, 1973.

Prepared by Gay Haroutunian, SLP, Carol Bryan, OTR, and Bev Grant, OTR, Machias, ME.

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Readings for Parents

No. 17

THE MENTAL HEALTH PROFESSIONALS

Who Are They?

There are many different professionals in the mental health field who work with children. The child psychiatrist is a medical doctor who specialized in mental health. He or she is the only one licensed to prescribe medication. Child psychologists, counselors, and child development specialists are trained to evaluate your child's mental and emotional health. There are also social workers, family therapists and consultants who help those who live or work with children.

There are similarities and differences in the work that these professionals do. It is, however, important to realize that the professional's title is less important than the person's experience with handicapped children. Often, it is helpful to have a team of these individuals work together in the evaluation process.

How Can They Help?

They can help children who have trouble expressing their feelings, or feel lonely and isolated from others. Handicapped children often feel poorly about themselves. Mental health professionals can help the child who is burdened with a poor self-image.

Sometimes children experience long periods of depression or they show a lot of tension in their behavior. They may get along poorly with other children and/or adults. Often they feel angry about being handicapped and have trouble expressing themselves in an appropriate and satisfying way.

Mental health professionals are trained to be helpful in these situations. They can listen to the communication of children in a special way. Through listening and understanding, working relationships are developed. This is what provides the foundation for any successful therapeutic program.

Some mental health professionals are also trained as play therapists. They try to understand a child's feelings by getting involved in his or her play. In this way, a therapist can help a child come to terms with a problem that he or she is experiencing, but is unable to express verbally,

With a child who is more verbal, counseling can also be very valuable. Often, handicapped children can express their feelings about themselves verbally, when they are encouraged to do so. Sometimes, they need the chance to do this with someone outside of their family.

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This helps them learn more about themselves and get additional feedback. They may also need help learning to be more aware of their feelings and how to express them. Child therapists can be very useful in these situations.

The Mental Health Consultant

It is not at all unusual for a handicapped person to be in need of counseling services during childhood, adolescence, or adulthood. Sometimes the individual needs the specialized support of a mental health professional. Professionals then work directly with the child and/or family.

They are also available to consult with teachers and others who may find it hard to understand a handicapped child's feelings. This type of indirect service can be a great aid to a child in his learning at school, especially for children with behavior problems. It can strengthen the educational program in a way that allows the child to begin experiencing success. This is not only important to the child's learning, but to his or her self-image.

Suggested Readings:

The Disabled and Their Parents: A Counseling Challenge by Leo Buscaglia, Charles B. Slack, Inc., 1975.

The Exceptional Parent (6 issues a year), P.O. Box 4944, Manchester, NH 03108.

Play Therapy by Virginia M. Axline, Ballatine Books, 1947.

Prepared by Robert M. Keteyian, Child and Family Therapist, Mental Health Consultant, Ellsworth, ME.

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Readings for Parents

No. 18

ADVOCACY

What Is Advocacy?

There are any number of answers to this question. Advocacy means those efforts which lead to improved services for your handicapped child and your family. It might start with your attempts to find out more about your child's disability and expand to include all actions on behalf of your child. It may mean such things as 1) seeking a clear diagnosis or appropriate services, 2) finding needed school programs or medical services, 3) keeping on top of new information, and 4) working with other parents.

Who Should Advocate?

Disabled people themselves. Parents and family members. Professionals. Interested members in the community.

Parents are the most effective advocates for their children. Legislators and bureaucrats are more likely and willing to listen to parents than to professionals. Most changes in laws or public policies have happened because of advocacy by parents. Joining forces with knowledgeable professionals usually creates an even stronger advocacy position.

If your child is young, begin now to think about building his or her self-advocacy skills. Most of us advocate for ourselves in any number of ways - even the child who insists he do something for himself, rather than have his sister do it for him.

Disabled children, teen-agers and adults need to gain practice in self-advocacy too.

When Should You Advocate?

From the beginning. As soon as you learn of your child's disability, try to determine what your next steps will be. You will want appropriate services. Inform yourself as to what these should be. Enter into partnership relations with those who will be working with your child.

Advocate for your child when things are going smoothly. Stay informed of his program. Ask questions.

Advocate during times of transition. When your child is moving from an infant program to a preschool, or from home services to group services, your advocacy efforts will be especially important.

Where Should You Advocate?

You will need to advocate in many different settings: your immediate or extended family, the community, with school officials and personnel, with members of the medical community.

All your energy cannot be spent on advocacy. You have other important things to do. Try to devote some time to thinking about how you can best use your "advocacy time." Which issues are of greatest concern to you? How can you get the best results for your efforts?

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Why Advocate?

The services you and your child receive will probably come closer to meeting your needs if you can be an effective advocate. The time you spend as an advocate should pay off with better services for your child, and this should make your situation more manageable.

Your efforts on behalf of your own child will probably put you in touch with others -- parents and professionals. As a group you can make a difference for many disabled children, including your own. There is strength in numbers. When conditions and opportunities improve for all disabled people your child will benefit.

How to Advocate?

We all have our own styles. Learn about yours. Are you a negotiater? A compromiser? A fighter? You may feel you can accomplish more by using the style that is comfortable for you. You may want to become more assertive. You may want to be less aggressive.

Enlist a friend, family member, or perhaps a counselor to help you study your advocacy efforts. What are the goals for your child? Where do you want your advocacy to lead? Are your current methods working? Would others work better?

Try to get some support. Advocacy is hard work and can be lonely. Look for other parents and friends to give you that support.

Finally, don't forget to take care of yourself. Give some time and attention to your own needs. If you can learn to advocate for yourself, as well as your child, your child will be the winner in the long run. Good luck in your efforts!

Suggested Readings:

The Child Advocacy Handbook by Happy Craven Fernandez, The Pilgrim Press, 1980.

How to Get Services by Being Assertive by Charlotte Des Jardins, Director, Coordinating Council for Handicapped Children, 407 South Dearborn - Room 680, Chicago, IL 60605, 1980.

How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies by Charlotte Des Jardins, Director, Coordinating Council for Handicapped Children, 407 South Dearborn - Room 680, Chicago, IL 60605, 1980.

Prepared by Jane Weil, Program Director, Machias, ME.